CCSD's

DISABILITY INFORMATION SHEET

No. 1
2001

Welcome to Readers of this first Disability Information Sheet published by the Canadian Council on Social Development (CCSD). This edition is part of an occasional series of information sheets that the CCSD will make available – as resources permit – as part of its commitment to produce and disseminate research on persons with disabilities. The CCSD plans to disseminate research information on persons with disabilities to a broad range of users, including the following groups:

- persons with disabilities
- families and friends of persons with disabilities
- governments at all levels
- non-profit groups
- social policy organizations
- service providers
- students and academics.

Each year, the CCSD receives countless requests for information about statistics and potential data sources related to persons with disabilities. This kind of information can be critical to people working with persons with disabilities, whether they deliver services directly, design programs and policies, or develop proposals, research projects, and program initiatives.

The short-term objective of the CCSD's disability research program is to identify information gaps in the area of persons with disabilities and to try to fill those gaps by using existing research databases that have not been fully explored. With funding support from Human Resources Development Canada, the CCSD will produce three information sheets this year. As resources permit, we will produce more information sheets on specific disability-related data needs identified by our readers. Ultimately, input from readers of these information sheets and other potential users of disability research information will help direct the topics covered.

In order to make the research information as accessible as possible and available to as many users as possible, each of these three initial information sheets will be produced in both English and French-language versions. Each issue will be mailed (or e-mailed) to potential user groups, with bulk copies sent to groups with large affiliated memberships so that they can distribute additional copies throughout their communities. As well, this disability research information will be accessible on a new subsite on the CCSD's award-winning website at www.ccsd.ca/drip (see page 12 for more details).

In this first issue, we present information about two important and frequently asked questions:

- What data sources are available to provide information on persons with disabilities?

and,

- What kinds of questions can be investigated using these data sources?

Canadian Data Sources on Persons with Disabilities:

One of the most commonly asked questions about disability research involves the availability of different data sources. People want to know *what kinds of data* are available on persons with disabilities. In this first section, we provide a brief overview of some of the major databases that are available in Canada today and several that will be available in the near future.

Some of these databases provide *cross-sectional* data. That means they provide a "snapshot" of information about people at the time the data were gathered. While respondents to a cross-sectional survey may be asked questions about things that happened over time in the past, the survey does not follow these same individuals to determine how things may change in the future. If a particular survey is later repeated, it draws upon a new sample of individuals that cannot be linked to the original survey sample. Most of the surveys listed below are cross-sectional.

Other databases provide *longitudinal* data. That means the same group of individuals is surveyed more than once.

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Typically, the same respondents are surveyed once a year or once every two years, which allows data users to track specific changes in the lives of these individuals. Longitudinal surveys listed below are specifically noted as such.

Unfortunately, most surveys do not cover the following subgroups of the Canadian population:

- people living in institutions
- people living on Indian Reserves
- those living in the Territories
- people living in barracks on Canadian Armed Forces Bases.

But of course there are a few exceptions. The Census is the most notable, as it covers the entire Canadian population. The APS, HALS, PALS, NPHS, CCHS and the NLSCY (described below) include the Territories, although sometimes in a separate survey. Only the APS and the Census gather data on people living on Indian Reserves. By excluding data on persons living on Indian Reserves and those living in the Territories, most survey databases do not include a representative sample of Aboriginal persons – since this population is highly concentrated in these two areas.

The following is a summary of some of the major Canadian databases which contain a "flag" for disability status. The years listed for each survey are the years in which that survey was, or will be, conducted. There is usually a gap of time between the gathering of survey data and the release of that data for analysis. Many of the surveys conducted in 1999 or later are not yet available for analysis.

Census (1991, 1996, 2001*)

- the Census "long form" – which contains the "flag" for disability status – covers 1 in 5 Canadian households. This large sample size permits analysis at lower levels of geography.
- contains basic socio-demographic information, such as education, labour market activity, income, and the like, but it does not identify disability type or severity.

* Note: the disability status "flag" in the 2001 Census differs from that of previous years.

General Social Surveys (GSS)

- information is gathered once a year, on average. Each of these GSS "cycles" features a special topic.
- covers adults aged 15 and older
- fairly small sample sizes – approximately 10,000 to 13,000 persons surveyed each time
- contains basic socio-demographic information, such as education, labour force activity, income, and the like, but does not identify disability type or severity.

Each cycle of the GSS features a specific topic of interest:

Time Use: GSS Cycle 7 (1992) and Cycle 12 (1998)

- contain extensive information on time-use, including paid and unpaid work, child care, household activities, perceptions of time, educational activities, recreational activities, and cultural activities.

Personal Risk: GSS Cycle 8 (1993)

Victimization: GSS Cycle 13 (1999)

- contain information on self-perceived health status, abuse, criminal victimization, and accidents/injuries
- contain information on lifestyle habits and crime prevention practices

Work, Education, Retirement: GSS Cycle 9 (1994)

- contains more detailed information than usual on education, labour force activity, employment history, skill development and usage, employer benefits, stress, use of technology on the job, retirement issues, and work interruptions

The Family: GSS Cycle 10 (1995)

- contains information on lifestyle habits, with particular focus on the family unit
- contains information on the balance of paid and unpaid work activities

Social Supports: GSS Cycle 11 (1996)

- contains information on assistance with daily activities, such as child care, meals, household chores, and so on
- contains information on self-perceived health status

Access to Information Technology: GSS Cycle 14 (2000)

- contains information on general use of technology and computers, work and educational background, computer technology in the workplace, volunteer work and computer use, development of computer skills, Internet and e-mail use, and non-users of technology

LABOUR & WORK SURVEYS:

There are two surveys which go beyond the norm in gathering rich data on the labour market experiences of individuals. The SLID provides data at both the individual level and the job level, in order to better capture the dynamic nature of the labour market experience. The WES focuses on the nature of the workplace itself and provides data at the individual level and the workplace level. Together, these two surveys can provide research data on "employment and persons with disabilities" at three levels of analysis: the individual, the workplace, and the job.

Survey of Labour and Income Dynamics (SLID)

First Panel: 1993-1998

- covers adults aged 15 and older
- provides both cross-sectional and longitudinal data
- SLID surveys are ongoing and they overlap, with new panels starting every three years. The longitudinal panels will gather information on the same group of individuals every year for six years.
- the first panel began with a sample of approximately 30,000 persons
- does not identify disability type or severity
- contains extensive information on labour force activity including detailed work history, wages and wage changes, self-employment, job

loss, job search techniques, job interruptions, employer characteristics, and so on

- contains information on income and income sources
- contains basic socio-demographic information, including education
- contains a disability-specific section which examines the role of disability in work activities

Workplace and Employee Survey (WES)

- the initial pilot survey was conducted in 1999; this survey is expected to be longitudinal, although details regarding the frequency and life span of the survey are still forthcoming
- sample covers both employers (about 8,000 work locations) and employees (about 25,000 in those workplaces)
- the employee questionnaire contains a screening question for disability status and asks:
  - Does your employer have any recruitment or career programs for employees with disabilities?
  - Have you ever participated in these programs?
  - Do you need altered facilities or equipment aids to help accommodate your condition?
  - Does you employer provide these altered facilities, equipment or aids to you?
- contains information about training opportunities and mobility within the workplace
- contains information on the use of technology on the job, benefits and leave packages, personal or family support, job vacancies, position within the marketplace, organizational structure, and a variety of work arrangements

HEALTH SURVEYS:

In 1994, the National Population Health Survey (NPHS) began. It was designed to provide both longitudinal and cross-sectional data on the health of Canadians over a 20-year period, with data being gathered every two years. In 2000, a second health survey began – the Canadian Community Health Survey (CCHS). The NPHS will continue as a longitudinal survey every two years. The CCHS will be a cross-sectional survey conducted each year, but the sample size and design will alternate. One year, the CCHS will gather provincial-level data and the next year, it will gather data at the level of the health region (a much larger sample size). For more information about health regions, see www.statcan.ca/english/concepts/health/regions.htm*

National Population Health Survey (NPHS) (1994/95, 1996/97, 1998/99, ongoing)

- covers persons aged 12 and older in households
- the longitudinal panel gathers information every two years on the same group of individuals. The longitudinal panel began with a

* Please note: Website addresses listed throughout these Information Sheets are current at the time of printing and may change in the future.

sample of approximately 18,000 persons.

- does not identify disability type or severity
- contains information on basic socio-demographic profile, education, labour force activity, some income information, limited information on disability supports and services, health, health care activities, lifestyle habits, recreation, food insecurity, stress of different types, and self-esteem (in some years only)

Canadian Community Health Survey (CCHS)

(2000, ongoing)

- covers persons aged 12 and older in households, although child-specific content is planned for the future
- conducted each year, alternating between health region survey (initial sample size of 130,000) and provincial survey (initial sample size of 30,000)
- does not identify disability type or severity
- contains similar information to NPHS

DISABILITY-SPECIFIC SURVEYS:

To gather detailed information on persons with disabilities, the Health and Activity Limitation Survey (HALS) was conducted in 1986 and 1991. Both surveys were post-censal, which means that information from the Census was used to generate a large sample of individuals with disabilities. In 2001, another post-censal survey will be conducted to gather detailed information on persons with disabilities. This new survey will be called the Participation and Activity Limitation Survey (PALS).

Health and Activity Limitation Survey (HALS)

(1991)

- covers all provinces and two territories in 1991
- covers adult population aged 15 and older in households. Separate surveys of children and residents of institutions exist, but have not been released for public use.
- sample includes approximately 26,000 persons with a disability and 65,000 without a disability
- contains information on disability type and severity
- uses detailed screening criteria
- contains detailed disability-specific information in a wide range of areas, including supports and services, technical aids and services, transportation, school and education, employment, income, recreation and lifestyle, and accommodation

Participation and Activity Limitation Survey (PALS)

(2001)

- will cover all provinces and three territories
- will cover adult population aged 15 and older in households
- will contain information on disability type and severity. Will provide a better distinction among non-physical disabilities than the 1991 HALS; will recognize a wider range of conditions than HALS; will permit more "fine tuning" of severity index

- will use new screening question that appeared on other Statistics Canada surveys from 2000 onward, therefore offering greater comparability across surveys
- will contain detailed disability-specific information in a wide range of areas, similar to HALS

SURVEYS ON YOUTH AND YOUNG ADULTS:

Throughout the 1990s, a number of surveys were conducted which focused on youth and young adults, particularly their school-to-work transition. The National Graduate Surveys provide information on recent post-secondary graduates and the School Leavers Survey provides information on youth who left high school before graduation. A new survey, the Canadian Longitudinal Youth in Transition Survey (YITS), will focus on youth and young adults with a particular emphasis on their transition from school to work.

National Graduates Surveys (NGS) Survey 1: 1990 graduates interviewed in 1992 and again in 1995; Survey 2: 1995 graduates interviewed in 1997

- sample sizes of 36,000 and 43,000, respectively
- contains information on training, education, and labour force activity

School Leavers Survey (SLS)

- covers adults aged 18 to 20 in 1991. The same individuals were followed-up in 1995.
- sample size of approximately 9,500 young adults
- information on lifestyle habits and education, including educational background, school difficulties, reasons for leaving school before graduation, future goals
- information on labour force activity, including future career goals and educational upgrading

Canadian Longitudinal Youth in Transition Survey (YITS) Cycle 1: 2000

- covers two cohorts of youth:
  - one cohort born in 1984, with a sample size of about 38,000
  - one cohort born between 1979 and 1981, with a sample size of about 29,000
- focuses on school-to-work transitions and factors involved in these transitions
- same individuals will be surveyed every two years (longitudinal data)
- survey will be ongoing

OTHER SURVEYS:

Adult Education and Training Survey (AETS) (1992, 1994)

- covers adults aged 17 and older
- sample size is approximately 42,000; about 7,600 with a disability
- provides information on training, education, and employment

Violence Against Women Survey (VAWS)
(1993)

- covers women aged 18 and older
- sample size of 12,300; about 2,000 with a disability
- provides information on lifestyle habits, particularly modifications to habits to avoid victimization
- provides information on abuse, physical security, and victimization

National Longitudinal Survey of Children and Youth (NLSCY)

(1994, 1996, 1998, ongoing)

- covers children aged 0 to 15 in households in 10 provinces. The first cycle of the NLSCY in 1994 included children aged 0-11; the third cycle in 1998 included children aged 0-15.
- follows children every two years (longitudinal), gathering information on a wide range of issues

Aboriginal Peoples Survey (APS) (1991 and 2001)

- covers all provinces and territories
- covers adults aged 15 and older who identify with an Aboriginal group and/or are registered under the Indian Act
- total survey sample of approximately 82,000 persons, with about 8,000 indicating a disability in 1991. Public-use tape contains data on 25,000 persons.
- 1991 survey provides detailed disability-specific information
- 1991 survey identifies type and severity of disability

Research Themes using these Canadian Data Sources:

The Canadian data sources listed above provide a number of research opportunities for users of disability data. While some of these data sources are not yet available for analysis and others may be difficult to access, that list can be a useful resource in planning research questions and themes that could be pursued using those data sources.

Employment Issues

Employment trends over time:

- job retention, the nature of periods of unemployment, and the nature of periods out of the labour force

- involvement in non-standard or precarious work, self-employment, multiple job holding, part-time work
- career mobility and job quality
- job stress and job satisfaction
- factors associated with positive employment outcomes

Work/family balance for persons with disabilities:

While almost all working people experience some conflicts in maintaining a balance between their work and family responsibilities, some persons with disabilities have a much more complex balancing act. For some persons with disabilities, their responsibilities for domestic labour may require extra time, particularly if they do not live in an accessible environment. Some possible areas of research here include the following:

- the relationship between domestic labour responsibilities and employment patterns
- the relationship between requirements for supports/services and employment patterns
- time use patterns and employment patterns

Older workers with disabilities:

Given the close relationship between age and disability, there has long been a concern for the situation of older workers with disabilities, many of whom became disabled later in life. Some possible areas of research here include:

- the labour market situation of older persons with and without disabilities during their pre-retirement years
- the retirement decisions of persons with and without disabilities in relation to their employment histories

Impact of training and education on employment for persons with disabilities:

Past research has indicated that increased levels of education and training have a positive impact on the labour force outcomes of persons with disabilities – such as higher rates of labour force participation and higher earnings – but this basic relationship has not been fully explored. There are now databases available that would permit a more detailed analysis of these issues, such as the following:

- the impact of education on job and wage mobility. For example, does increased education have a similar impact on career trajectories for persons with and without disabilities?
- the impact of education on the school-to-work transitions of young people with disabilities
- the impact of information technology skills on employment

Labour market conditions:

Recent changes in the labour market might affect persons with and without disabilities differently. But how are persons with disabilities affected by this segmentation of the labour market and changing conditions? Research currently underway indicates that

during the mid-1990s, persons with disabilities in the paid labour force were increasingly more likely to be among the lowest wage earners. This suggests that persons with disabilities might have had fewer opportunities to find and maintain jobs in some labour markets, particularly those in the core sector (typically associated with more secure jobs, higher paying jobs, those with better benefits and greater potential for upward mobility, and so on). Further analysis could be done to determine what transformations have been taking place in the labour market and how these changes have affected persons with disabilities.

Income

Income adequacy:

- What is the pattern of income adequacy for persons with and without disabilities over time?
- What characteristics are associated with persons being trapped in low-income situations? How does this differ for persons with and without disabilities?
- What is an adequate income for a person who has significant costs related to a disability, such as the costs of supports/services, and the like? (Answering this question would require data from PALS, plus additional data that have not yet been gathered.)

Income patterns over time:

- What is the rate of persons with disabilities leaving income support or replacement programs – such as CPP/QPP, social assistance, Employment Insurance, Workers' Compensation, and so on – for earnings over time? Is there a sustained pattern?
- What impact does a change in disability status have on income sources over time?
- What impact does a change in labour force activity have on income sources over time?

Supports and Services

Until the new PALS is released, there are few survey databases that can provide information on supports and services for persons with disabilities. For ongoing research in this area, see information from the Office for Disability Issues at HRDC at http://www.hrdc-drhc.gc.ca/hrib/sdd-dds/odi/documents/disability_bulletin/toc.shtml

- What is the impact of requirements for supports and services on other aspects of life, such as recreation, health care patterns, food security, employment, income adequacy, and so on?

Citizenship

Citizenship issues cover a wide range of topics. The following areas might be explored:

- personal security issues
- health issues, such as the relationship between health and disability, use of the health care

system, requirements for and use of medications, and so on

- lifestyle issues, such as patterns of recreation, sports, and leisure activities, usage of the Internet in various aspects of life, and so on
- food security issues, such as the use of food banks and other charities, incidence of running out of money to buy food, and so on

Children with Disabilities

Research questions involving health care, school patterns, activities, poverty, and the like can be explored for some age groups of children using the NLSCY, NPHS, and CCHS. As well, a wide range of activities – such as educational activities, employment patterns, and lifestyle pursuits – for young adults with disabilities will be covered in the YITS when it becomes available.

Aboriginal Persons with Disabilities

There are only two national surveys that can identify Aboriginal persons with disabilities: the APS (1991 & 2001) and the Census (1991, 1996 & 2001). Although dated, information from the 1991 APS has not been fully explored for issues pertaining to Aboriginal persons with disabilities.

As noted earlier, the exclusion of people living in the Territories and those on reserves from most databases results in a significant proportion of the Aboriginal population not being represented in the data that are collected. Although some databases attempt to identify Aboriginal persons living off reserves, it is often difficult – if not impossible – to identify different groups of Aboriginal persons, particularly persons from the Métis Nation.

In lieu of having national-level databases, information gathered by various groups at the community level – such as in program or administrative files, registries, and so on – should be considered for research analysis. However, these data would best be analyzed by those from the relevant communities, particularly those who have an understanding of how the data were gathered, what biases might exist, what meaning is attached to the data within the community, and so on.

Social Indicators

Another popular area of research among data users has been the development of a wide range of "social indicators" in order to construct an accountability framework for persons with disabilities. Background research in support of this would require data from surveys that are repeated at equal intervals over time (such as yearly, every second year, or every three years), with common content collected in each survey. It would also require very careful consideration of the kinds of indicators desired. One possible research task in this area would be to try to develop a methodology to use existing data or gather new data that could be used to construct concrete indicators of well-being for persons with disabilities.

DISABILITY INFORMATION WEBSITE

The CCSD has created a new subsite on our website in order to provide centralized access to all of our disability-related resources. Our objective is to make this subsite – called the Disability Research Information Page (DRIP) – as accessible as possible to people with disabilities. Materials in the subsite will be available in both English and French.

Wherever possible, *Web Content Accessibility Guidelines* have been adhered to in the design and creation of the site. Whenever possible, materials will be presented in various formats (for example, HTML and PDF), so that a variety of choices will be available to all users. We believe that clarity of content, simplicity of design, structural integrity and ease of navigation are essential elements of any good website, and they provide benefits to all users, especially those with disabilities. Similarly, providing alternate ways of accessing information will prove useful to people with and without disabilities.

Users of the website will be encouraged to provide us with feedback on our progress towards our website accessibility objectives. Users will have the option of providing their feedback using a web survey form, or via e-mail or by telephone. See the box on page 2 for all the CCSD's coordinates.

FEEDBACK PLEASE:

We hope you will find this Information Sheet useful in your work, but we need to know. So please give us your feedback on what you like – or don't like – about anything here: the topics chosen, the ways in which the information is presented, the language used, anything at all.

To do so, you can send us a letter or an e-mail at the coordinates on page 2. Or you can log onto our website at ***www.ccsd.ca/drip*** *and provide your feedback directly on-line.*